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## A Call for Integrated and Coordinated Palliative Care

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## **Abstract**

Integrated palliative care is viewed as having the potential to improve service coordination, efficiency, and quality outcomes for patient and family carers. However, the majority of Canadians do not have access to regional, comprehensive integrated palliative care. Work needs to be directed towards planning palliative care services that is integrated into the health and social care system. To further this goal it is important to have a conceptual understanding of the meaning of integrated care and its expression in organizational models for the provision of palliative care.

The literature has shown that palliative care can have a positive impact on the quality of life of patients.<sup>1-6</sup> However, the provision of palliative care is often still less than optimal.<sup>7, 8</sup> The majority of patients do not have access to the benefits of a regional, comprehensive, integrated palliative care program. Rather, patients are not always able to receive care in their preferred place of care, often transfer between sites of care and experience unnecessary hospital admissions as they near the end of life. This report previews the literature on service integration and its implications for patient and family carer access to comprehensive and coordinated palliative care. For the purposes of this paper, the World Health Organization's definition for integrated care will be employed describing integrated health care as; ' the organization and management of health services so that people get the care they need, when they need it, in ways that are user-friendly, achieve the desired results and provide value for money'.<sup>14</sup>

Integrated care is viewed as an important framework to enhance quality of care, efficiency, and patient satisfaction in health and social care systems.<sup>9-11</sup> It is commonly viewed as an organizing principle for care delivery with the aim of achieving improved patient care through better coordination of services. However, despite the popularity of developing integrated models of care the lack of a common language has hampered our understanding of its meaning. A recent review of the literature on integrated care revealed some 175 definitions and concepts.<sup>12</sup> The diversity of definitions applied to integrated care has resulted in diverse approaches to integration resulting in unequal access to palliative care.<sup>13</sup>

Moreover, integrated care means different things to different people, including patient, the health care provider, and the health policy analyst.<sup>14</sup> For the patient and family, integration of care means health and social care that is seamlessly easy to navigate. Patients and their families want healthcare service that both minimizes the steps towards securing access to care and avoids redundancy. Having to repeat their story to care providers causes patients to feel as if the system is uninformed on their care needs. For health care providers, integration of care can mean that funding and provision of services and their support systems are coordinated. For the policy analyst, integration of requires de-compartmentalization of decisions on policies, financing, regulation, and delivery. De-compartmentalization occurs when a network of public, private, and voluntary health and social care services are brought together (as opposed to looking at the public sector in isolation).<sup>14</sup>

When considering the integrated care needs for the user, provider, and analyst, a range of strategies emerge in the literature that dictate how to develop an integrated care service model. The literature also coalesces into a common taxonomy that classifies the more common approaches on the application of integration of service models.<sup>11, 15-17</sup>

An organizing framework based on a taxonomy for the integration of care would play an important role in facilitating the description and comparison of different integrated service models which is useful for the development of policy development, as well as the implementation and evaluation of integrated service models. It is recognized in the literature that service integration is enabled through a range of processes that may focus

on systems, teamwork or professional behaviors. The types of integration are viewed as having interconnected roles on the system (macro), organizational (meso) and clinical (micro) level.<sup>17, 18</sup>

1. System. Coordinating and aligning policies, rules and regulatory frameworks that promote horizontal and vertical integration (macro level)
2. Organizational. Inter-organizational relationships, coordinating structures and governance mechanisms, to deliver comprehensive services to a defined population. (meso level)
3. Administrative. Key support functions that include financial, management and information systems structured around service delivery (micro, meso, macro level)
4. Clinical. The coordination of patient care across time, place, and discipline. This can include guidelines, care paths, inter-professional education and multi-disciplinary teamwork. (micro level)
5. Normative. Developing shared values, culture and vision across organizations, professional groups and individuals. (micro, meso, macro levels)

There is a lack of evidence about what integrative types are best suited to a particular setting. The view is that the specific goals of the initiative for integrated care will shape what type of integration is suitable within a particular setting. Decisions about the type of service integration most relevant to a particular initiative will be guided by the goals

of the project, stakeholders involved, existing arrangements, resources that are available and the scale of the initiative.<sup>15</sup>

The extent of service integration witnessed in a particular initiative can also vary in intensity, ranging from full integration, involving the pooling of resources, thru to the coordination of services where service delivery is provided by existing services that share clinical information and manage patient transition between services, thru to service linkage that simply involves sharing clinical information between service organizations. It is now widely accepted that ‘one size of integrated care does not fit all’.<sup>11, 15</sup>

A number of factors have been identified in the literature as either facilitating or undermining efforts towards integrated care. These factors include the size and complexity of the change effort; presence of leadership from senior management; the presence of a supportive organizational culture; availability of information technology that supports data-sharing; communication across health and social care teams; and, resources such as budgeting, adequate staffing and a reasonable implementation timeline.<sup>11, 15</sup>

### **Integrated care in palliative care.**

The WHO defines palliative care as an approach that improves the quality of life of patients and their families who are facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification,

impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.<sup>19</sup>

The WHO's definition of palliative care has implications on how the provision of palliative care is situated in a national health system.<sup>19</sup> First, national health systems should include palliative care in the continuum of care linking it to prevention, early detection, and treatment programs. Palliative care services should also be provided alongside potential curative treatments and adapted to the needs of patient and families as the disease progresses. Integrating palliative care within regular treatment offered to patients with life-threatening disease is supported by a growing amount of evidence that demonstrates the effectiveness of palliative care on the improvement of the quality of life of patients.<sup>1-6</sup> Second, palliative care services need to be provided in accordance with the principles of universal health coverage where all people should have access to palliative care services that are essential, safe, affordable and effective.

The traditional focus on specialist palliative care teams caring for people with cancer in a hospital setting has been expanded to include a wide range of life-limiting disease groups and settings of care. Accompanying this expansion have been societal changes in living and social circumstances where traditional family caring roles cannot be taken for granted; individualistic and consumer choices have placed a greater demand on patients in determining and tailoring their healthcare, including the opportunity to be cared for and die in their place of preference. Given the increasing numbers and expanding profile of people with life limiting illness, a population health approach to planning is required to

inform the development of any model of palliative care that integrates with other services. Embedded in this approach is the acknowledgement that communities play an important role derived from possessing unique knowledge of their locality and thus most able to address disparities by recognizing the socioeconomic and geographic variables present in their locality as well as the relationships necessary for effective community development of integrated palliative care. <sup>20</sup>

An obvious reference point towards articulating our understanding of what are the key elements of integrated palliative care can be traced back to the WHO definition of palliative care, that expresses the value of a holistic approach to care, recognizes both the patient and family as the unit of care and the early application of palliative care in the course of the illness. <sup>19</sup>

In a European Commission funded project, InSUP-C (patient centred integrated palliative care pathways in advanced cancer and chronic disease, 2012-2016; available at: <http://www.insup-c.eu/>) an international team of researchers have endeavored to identify the best way to deliver care to people at the end of life. Based on a consensus of the InSUP-C experts their definition of integrated palliative care involves *'bringing together administrative, organizational, clinical and service aspects in order to realize continuity of care between all actors involved in the care networks of patients receiving palliative care. It aims to achieve quality of life and well-supported dying process for the patient and the family in collaboration with all care givers (paid and unpaid)'*.<sup>21</sup> One objective



of the InSUP-C initiative, that merits attention in this report, has included identifying the requirements of promising practices for integration of palliative care in Europe.

An activity related to this objective was, via expert consensus, building a taxonomy for integrated palliative care applicable across diseases, healthcare sectors and systems.<sup>22</sup>

Consisting of eight categories that include elements on service configuration the taxonomy covers the process and structure of IPC initiatives.<sup>22</sup> Categories range from:

1. Type of initiative: guidelines, pathway, model
2. Level of care: primary (General Practitioner, nursing service, community care), secondary (specialist physicians, nurses, hospital, inpatient hospice) tertiary (cancer centres, academic training centres)
3. Sector: inpatient, homecare
4. Time frame of intervention: early integration, concurrent, end of life
5. Focus of function: treating function, advising/consulting, training
6. Collaboration: network, protocols, team, case management
7. Key contact: GPs, non-palliative care specialist, palliative care specialist

The taxonomy developed by the InSUP-C group represents a substantive step towards how we define and understand integrated palliative care. The complex character of the taxonomy reflects the wisdom that the expression of integrated palliative care is influenced by context or situation. Decisions about the type of integration, as stated

earlier, are guided by project goals, stakeholders involved, existing arrangements, resources that are available and the scale of the initiative.

Key learnings from the InSUP-C experience included recommendations on how to further integration of palliative care in Europe.<sup>22</sup> These recommendations reinforced the notion that integrated care is about improving the care experience for patients and their families. Further, organizational considerations should emphasize the importance on establishing formal structures and frameworks that promote care quality, communication and smooth patient transition across settings. At the regional level consider should stress the importance of integrated information systems that promote continuity of information across settings of care. Finally, at the health system level, accountability and evaluation mechanisms should be essential to measure and assess the impact of service integration on quality of care, user satisfaction and effective organizational relationships.

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